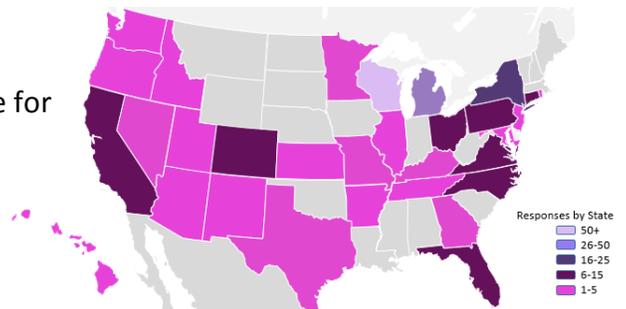


Dementia Priorities Identified from a National Survey

Following the 2011 National Alzheimer’s Project Act (NAPA) law, the federal government published the first National Alzheimer’s Plan in 2012 with annual updates and recommendations thereafter. The federal government’s plans and efforts for dementia follow the National Plan and its recommendations. With funding from The Retirement Research Foundation, a collaborative team from CCAL: Advancing Person-Centered Living and the UB’s Institute for Person-Centered Care conducted a national online survey with a broad spectrum of Americans with personal or professional experience with dementia, including Alzheimer’s. The study used a two-round Delphi Approach to gain consensus about what people see as the important priorities for dementia and how these priorities compare with NAPA’s priorities and recommendations.

Potential survey participants needed to have access to and use email, however paper versions were made available via mail. In order to reach people who at least had some personal or professional experience with dementia or with individual(s) living with dementia, email invitations were disseminated through a wide network including: grassroots dementia groups, the Pioneer Network’s state coalitions, national aging service and provider organizations, and consumer advocacy organizations such as Consumer Voice among others. People who responded to the email invitation were made aware that participation would include responding to at least two rounds of survey questions and were offered the option to take the survey online or to be sent a paper copy of the survey. While the Delphi methodology is more time intensive, this methodology was selected because it provided the best means of gathering and combining opinions and developing a broad consensus.

Respondents to the survey included a broad array of people including: individuals living with dementia (3%), those who care for them at home and in long-term care settings, other family members and advocates, aging service professionals, health practitioners, and others. Most participants were women (85%) In Round One 388 people participated and in Round Two, 301 people participated. Responses were received from residents of 31 states and DC.



Demographics

Ethnicity	%	Age	%
(n=249)		(n=246)	
White	91	18-29	6
Hispanic	2	30-39	7
Afr. Amer.	2	40-49	15
Asian	2	50-59	32
Decline	2	60-69	31
Other	1	70-79	8
		80-89	1

Key Relationships with People Living with Dementia

Current Relationship	%*	Previous Relationship	%*
(n=140)		(n=179)	
Parent	42	Parent	34
Spouse/Partner	20	Spouse/Partner	3
Friend	23	Friend	16
Brother/Sister	6	Brother/Sister	1
Grandparent	5	Grandparent	29
In-law	5	In-law	9
Uncle/Aunt	2	Uncle/Aunt	8
Other	0	Other	8

* Total exceeds 100% because some respondents indicated more than one relationship

Round One (April 8-25, 2014): Participants were asked to describe the needs of people living with dementia and their care partners and to identify priorities for federal policy and publicly funded research. Responses from Round One were analyzed and themed groups of potential priorities were identified.

Round Two (May 24-June 6, 2014): Participants were asked to rank the themes by priority. The following are the ranked findings from the survey. Details in the meaning of each priority for people living with dementia and their care partners are provided along with quotes from participants commenting on the each set of priorities supporting or extending the themes.

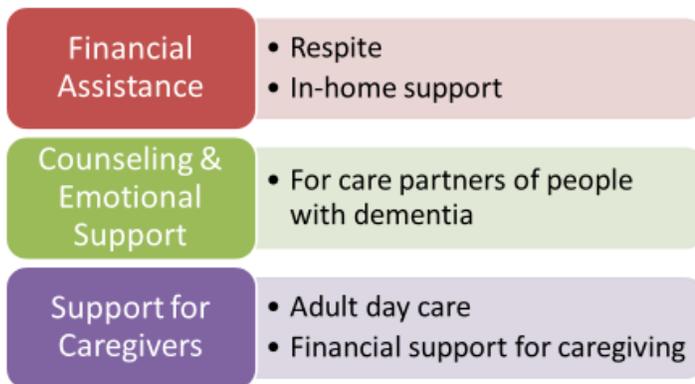
Dementia Priorities Identified by National Survey



Participants found it very difficult to choose between topics. Several comments were recorded stating that the need is so great that everything needs to be ranked #1!

“This was a very difficult question. ALL of these topics are of great need. I had a very difficult time ranking them. As this population increases we are going to need more and more to help support them and their families/caregivers long term.”

Tied # 1 - Priorities for Caregiver Support



“If I had a dollar to allocate, I might divide it equally among these priorities”

“Very difficult! All are important. However, caregivers wouldn't have as much stress and need emotional assistance if they had the supports they needed for their loved one in the home”

“HARDEST job that I have ever done. If you haven't done it, you don't have any idea how hard it is. Not much support for the caregiver!!

“Many family caregivers, male and female, give up working outside the home to become a fulltime caregiver because they can't afford outside help. Caregiving can last years, and the resulting loss in

income and lack of employability (who's going to hire someone who spent the last 5 years caring for his mom?) afterwards can devastate a family caregiver”

Tied #1 - Priorities for Long-Term Care

Provide Home & Community-Based Services	<ul style="list-style-type: none"> Resources to support aging in place (transportation, affordable assisted living, home delivered meals, care management, adult day services)
Skilled Workforce	<ul style="list-style-type: none"> Build and develop dementia care knowledge and skills for LTC workforce
Increase Standards & Oversight	<ul style="list-style-type: none"> In assisted living, nursing homes & hospitals Avoid use of antipsychotics to manage behavioral expressions

much of the long-term care system in place now is for people whose disease has advanced to critical stages, but there is still a great deal of need for less intensive, intermediate-term care for people with dementia.

"First we need home and community based services so those with dementia can remain in their homes as long as possible. Then, we need a competent workforce and nursing homes that provide quality person centered care. We need it all!"

"Regulations are inconsistent at best... Would like to see some broader rules from the federal level that are enforced at...a much higher standard."

"The standards for AL and Adult Day need to include cultural competence... What do they know about the cultures they/hope to serve?"

"There is a big need for long-term care that supports people in the early to mid-stages of the disease. Too

2 - Priorities for Research

Cure	<ul style="list-style-type: none"> Prevention, cure and treatment-related research highly supported No specific topics suggested
Care	<ul style="list-style-type: none"> How to reduce stress, fear, & distress for people with dementia and care partners Person-centered care and practices Complementary therapies and non-drug approaches
Quality of Life	<ul style="list-style-type: none"> Educational research to inform all professionals (health, law) Impact of dementia on individuals, family and society

"Based on research, early diagnosis and caregiver support provide the greatest impact. Early diagnosis allows for medications that slow the progression of the disease; time to plan while the individual has the capacity...make end of life decisions and care decisions. Care giver education and support decreases or delays future placement in nursing homes...Medical research on the causes of irreversible dementia will have the greatest long term impact decreasing the incidence"

"Aging in place and homelike environments are so important to the patient and the caregiver's desires for the loved one. Support furniture, for bath and living spaces, is so expensive! Please look at that as you plan for technology, which may not be useful or accessible for the average home"

3 - Priorities for Education & Training

Develop Knowledge & Skills	<ul style="list-style-type: none"> For all caregivers: at home and in long-term care; hospitals; primary care; public agencies
Person-Centered Care and Non-Drug Approaches	<ul style="list-style-type: none"> Communicate with and including the person living with dementia Complementary therapies (e.g. music, massage, aromatherapy)
Incentivize Dementia as a Specialty	<ul style="list-style-type: none"> To increase the number of health professionals with person-centered dementia care skills

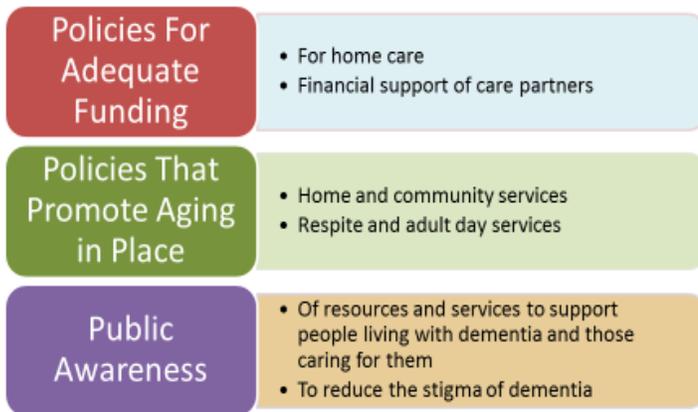
"Need \$\$ for supporting more diverse ethnic and racial physicians and nurses - not just Care Assistants"

"Investing in training family caregivers and healthcare/social workers will prevent premature institutionalization of people w/ dementia"

"Facilities need to know now as they currently are doing the crises intervention because the other supports aren't in place yet..."

"It would be good to look at what is working in other countries and ask them to share what they have learned. The US needs a culture change, and become a more compassionate people toward all elderly"

4 - Priorities for Advocacy & Awareness



“Dementia should be #1 health care policy priority precisely because it will lead the way toward greater compassion and services for people with other disabling diseases”

“I would make support for family caregiving the number one priority for public health policy, independent of diagnosis or condition. Aging in place when it is desired and appropriate but also support for positive transitions to new settings that may promote thriving”

“The general public has to become aware of the difficult behaviors of people with dementia and support the caregiver, be patient with the patient. The number one priority for the nation now is the mentally ill and gun control. Dementia isn't necessarily violence oriented”

Interviews

In addition to the online survey, confidential interviews were conducted with 27 leaders in the field of aging. Of these leaders only 16 stated they are ‘familiar’ or ‘somewhat familiar’ with NAPA’s purposes and strategies. The remainder did not know about NAPA and were not able to comment further. Given the prominent organizations that these leaders were from, their responses suggest that NAPA’s strategies and work is not being disseminated sufficiently.

Of the leaders who were familiar with NAPA, the following are some of their key suggestions what NAPA should focus its goals and priorities on:

- “Would like to see NAPA focus on person-centered care, use current knowledge rather than traditional medical/clinical orientation, and want them to focus more broadly across all settings.”
- “We need to build a really strong community infrastructure. I’m not talking just about home care. I mean a true community-wide effort to support people with dementia to live in the community. The National Plan should reach out more broadly about community aspects – care, housing, transportation, community development, and economic development.”
- “Focus on family and the informal supports. With billions of dollars in unpaid care, more can be done to help family caregivers. You have to help the people and the caregivers who are dealing with dementia now.”
- “As new health care delivery models are being developed there is flexibility with how money is being spent on services. These new models can address how to pay for these services. We need to think outside the box.”

Discussion

The lion’s share of federal resources and dollars are invested in finding a cure and treatments for Alzheimer’s. These are critically important objectives and ranked high in the survey. The priorities that ranked highest from the universe of possibilities, however, are focused on dementia CARE. This finding is in tandem with a recently

released RAND Corporation report titled, “Improving Dementia Long-Term Care: A Policy Blueprint”. The RAND report identified five areas for immediate policy attention of which the survey’s top two identified priorities (caregiver support and long-term care) are two of its five priorities. NAPA’s meeting focus to date has been mostly on the CURE and CLINICAL aspects. The survey findings and RAND report suggest that NAPA should consider as high a priority and focus on dementia CARE.

The specific items identified within the top priority categories - financial assistance for respite and adult day care, counseling and emotional caregiver support programs, home and community-based services, research for the cure and care, training and education for the wide array of care partners and professionals involved in dementia care, public awareness, and increasing LTC standards and oversight – all come with financial implications. Financial implications are a key topic for NAPA’s consideration because it underpins significant aspects of dementia care. We suggest “addressing” this key topic as a necessary first step towards a viable national solution.

There were two items identified in the survey that especially stood out because conventional wisdom holds them as important. First, while survey respondents did identify “advocacy and awareness about dementia” as a need, the item ranked as not very important. We postulate that this is because people, in general, perceive advocacy and public education as helpful but not immediately beneficial to care or to their personal caregiving needs. Second, respondents ranked “involving the person with dementia in decision-making” as not very important. This is likely a result of the widespread lack of understanding of the dementia condition itself as well as needing to be educated about person-centered care practices. The Affordable Care Act mandates the delivery of person-centered care practices by service providers receiving payment by CMS. Person-centered care practices have not yet been a focus of NAPA’s efforts and we recommended they be addressed.

It is significant that so few leaders in aging services know about NAPA. If NAPA’s efforts are to be effective and successful, there needs to be active integration with the private sector as well as the agencies within the federal government. Currently there is no system in place to actively coordinate and link federal and private sector efforts to maximize beneficial outcomes. For the U.S. to make significant progress in dementia, this too will need to be addressed.

Respectfully submitted

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